

FIRST NATIONAL FORUM ON SECONDARY FRACTURE PREVENTION

Rydges Hotel, Sydney Airport, Sydney, NSW

Meeting
Report

First National Forum on Secondary Fracture Prevention

Dear Colleagues,

On 20th November 2015, representatives from 22 organisations gathered in Sydney to attend the inaugural National Forum on Secondary Fracture Prevention.

This meeting was a direct result of a position Paper Published by the Australia & New Zealand Bone and Mineral Society (ANZBMS) and endorsed by a large number of organisations and key stakeholders. The Paper drew attention to the appalling lack of effective osteoporosis care in Australia, and the shocking fact that 80% of patients who suffer a fragility fracture receive no treatment to prevent further fractures.

The case for addressing the lack of osteoporosis awareness, both among health professionals and patients, has been made repeatedly over the past 15 years. However, despite several 'white papers' published in 2001, 2007 and 2013, and even the inclusion of osteoporosis as part of the 7th Australian National Health Priority¹ in 2002, little or no progress has been made. One reason for this failure was the lack of a peak body that encompassed ALL stakeholders to speak with one unified voice.

The First National Forum on Secondary Fracture Prevention is a loud and clear call to action. The aim is to enable all stakeholders to develop a shared understanding of the key elements of a national approach to secondary fracture prevention, and to forge a National Alliance to ensure strong advocacy for the uptake of this approach by Federal and State Governments. Similar Alliances have been formed overseas, and particularly in the US, and these Alliances have been extremely successful in getting heard by Governments that would not otherwise have listened.

It is my sincere hope that this forum will mark the first meeting of a successful National Alliance that will go forward and conquer the unnecessary burden of secondary fragility fractures on the ageing population of Australia. In the pages of this report I hope you find the evidence to convince you to take action.

In the words of Nelson Mandela:

"We know it well that none of us acting alone can achieve success. We must therefore act together."

Professor Markus Seibel, MD PhD FRACP
Immediate Past President, ANZBMS

¹ Australian Institute of Health and Welfare, AIHW National Health Priority Area 7, Arthritis, osteoporosis and other musculoskeletal conditions <http://www.aihw.gov.au/arthritis-and-musculoskeletal-conditions/>

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Participating organisations

 <p>Public Health Association AUSTRALIA</p>	<p>AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE</p>	 <p>GARVAN INSTITUTE</p>	<p>Endocrine Nurses' Society of Australasia Inc.</p> 
	 <p>Australian & New Zealand Society for Geriatric Medicine</p>	 <p>ANZHFRA Australian & New Zealand Hip Fracture Registry</p>	
 <p>Australian Government National Health and Medical Research Council N H M R C</p>	 <p>The Royal Australasian College of Physicians</p>	 <p>ANZBMS</p>	
 <p>NSW Carers AUSTRALIA</p>	 <p>ROYAL AUSTRALASIAN COLLEGE OF SURGEONS</p>	<p>AUSTRALIAN PHYSIOTHERAPY ASSOCIATION</p> 	
 <p>oa osteoporosis australia</p>	 <p>THE ROYAL AUSTRALIAN COLLEGE OF GENERAL PRACTITIONERS</p>	 <p>OSTEOPOROSIS NEW ZEALAND <i>Better bones, fewer fractures</i></p>	
 <p>Australian Rheumatology Association</p>	 <p>AOA AUSTRALIAN ORTHOPAEDIC ASSOCIATION</p>	 <p>esa endocrine society of australia</p>	
 <p>DAA Dietitians Association of Australia</p>	 <p>ANZAC RESEARCH INSTITUTE</p>	 <p>Institute for Health & Ageing</p>	

Introduction

The majority of Australians who suffer osteoporotic fractures are neither investigated nor do they receive appropriate treatment. As a consequence, many of these men and women experience further fragility fractures, which we know lead to significant morbidity (illness) and excess mortality (death).

This appalling lack of care exists in the face of widely accessible and highly efficacious management strategies to improve bone strength and prevent falls. It exists despite repeated and loud calls for action. Although osteoporosis has become part of the 7th National Health Priority Area in 2002, little progress has been made since then. This deficiency was again highlighted by a recent ANZBMS Position Paper, which called for a National Forum on Secondary Fracture Prevention.

This forum has a single purpose: To forge an alliance of all key stakeholders, which then translates the clear evidence for the effectiveness of appropriate interventions in reducing the risk of re-fracture into tangible health benefits for Australians. Only together do we have a strong voice to advocate to government and formulate initiatives that will make a real difference to our patients' lives.

Overview

The purpose of this first National Forum was:

- ♦ To understand and review the evidence base
- ♦ To highlight the necessity for action
- ♦ To explore whether a National Alliance for Secondary Fracture Prevention is the way forward
- ♦ To ensure a National Alliance meets the needs of individual organisations
- ♦ To have a clear plan to take the proposed National Alliance forward

Attendees

Bruce Armstrong

Public Health Association

Heather Buchan

Australian Commission on Safety and Quality in Healthcare

Jackie Center

Garvan Institute of Medical Research

Fun Chan

Endocrine Nurses Society of Australia

Jacqui Close

ANZ Hip Fracture Registry
Australia New Zealand Society for Geriatric Medicine

Melita Daru

Osteoporosis Australia

David Findlay

Australia New Zealand Orthopaedic Research Society
National Health and Medical Research Council

Kirtan Ganda

Australian New Zealand Bone and Mineral Society

David Jesudason

Royal Australasian College of Physicians

Mark Kotowicz

Endocrine Society of Australia

Colleen Langron

Australian Physiotherapy Association

Andreas Loeffler

Australian Orthopaedic Association

Greg Lyubomirsky

Osteoporosis Australia

Gabor Major

Australian Rheumatology Association

Paul Mitchell

Australian New Zealand Bone and Mineral Society
Osteoporosis New Zealand

John Parikh

Royal Australian College of General Practitioners

Ann Robinson

Endocrine Nurses Society of Australia

Kerrie Sanders

Institute for Health and Ageing, ACU

Davor Saravanja

Australian Orthopaedic Association
Royal Australasian College of Surgeons

Markus Seibel

Australian New Zealand Bone and Mineral Society
ANZAC Research Institute

Natalie Stapleton

Dietitian Association of Australia

Katherine Stone

Carers New South Wales

Secondary fracture prevention: Key elements of the case for a national approach

Update on the burden of disease

Prof Kerrie Sanders

Institute for Health and Ageing, Australian Catholic University

Cost and quality of life burden

The risk of sustaining a further fracture at least doubles for a person who sustained a fracture within the last 5 years. In a cohort of over 900 people that had sustained a fracture in the prior two weeks, 1 in 5 had sustained a previous fracture within the past 5 years.

"There are strategies and treatments that can very easily be implemented that will reduce the risk of subsequent fracture."

Government statistics hugely underestimate the burden of disease, as acknowledged by the AIHW. The systematic underestimation can be explained in a number of ways:

1. Osteoporosis is a silent disease until you have a fracture
2. AIHW take prevalence data from the National Health Survey – a self-reported questionnaire
3. Quality of life (QoL) impact is not well estimated as it is measured from those with a diagnosis of osteoporosis rather than fracture
4. Cost is also significantly underestimated as only those fracture patients admitted to hospital and get the appropriate DRG code linked to their hospital admission record. Notably, not all patients who sustain a fracture are coded as such.

Other organisations also grossly underestimate the burden as they tend to rely on AIHW statistics that are underestimates.

Based on government statistics and AIHW/ABS data it was estimated in a recent report² that there were 3,770 fractures associated with osteoporosis in 2012 with a total cost estimate of \$87 million. However, population-based research indicated

² Arthritis and Osteoporosis Victoria (2013). 'A problem worth solving' Elsternwick: Arthritis and Osteoporosis Victoria.

that a more accurate estimate is likely to be 140,882 osteoporosis associated fractures in 2012 (Figure 1), and \$1.6 billion in direct costs.³

The Aus ICUROS⁴ study recruited over 700 Australian adults (aged ≥50) within 2 weeks of a low to moderate energy fracture of the hip, wrist, humerus, vertebrae or 'other' fracture type.

The prospective study design included 18-months follow-up and looked at every health and community service patients used that was directly related to their fracture.⁵

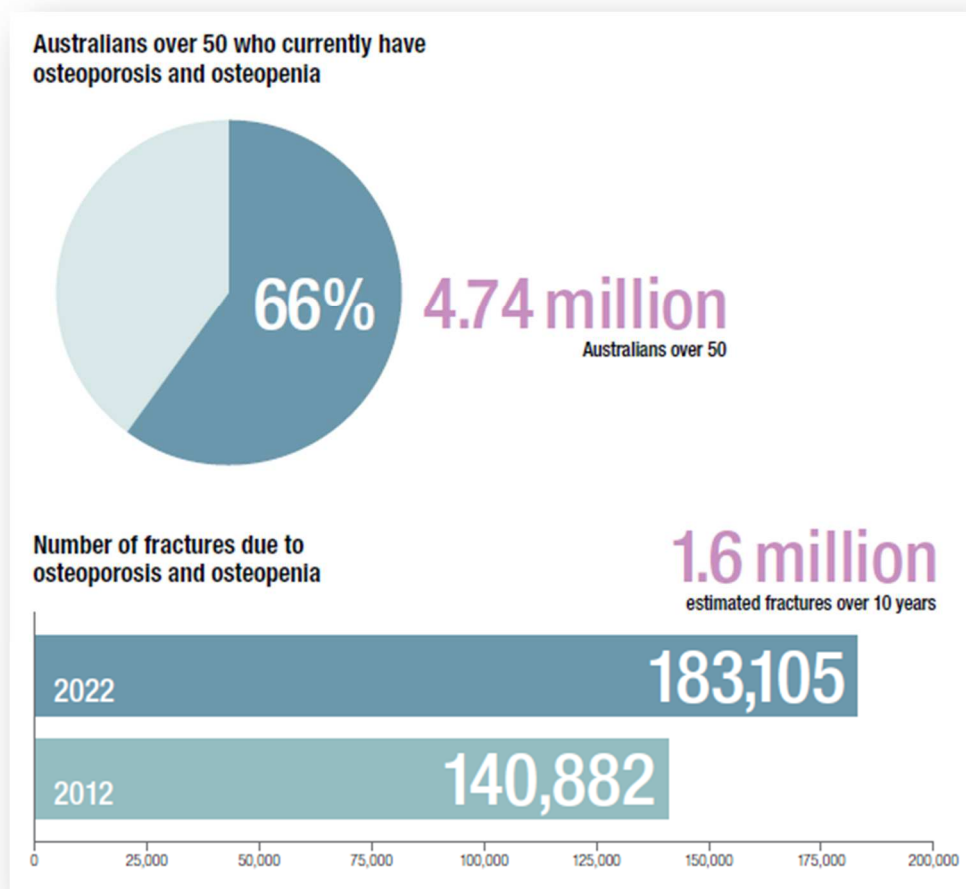


Figure 1. Estimated fractures due to osteoporosis in Australia.

[Source: Osteoporosis costing all Australians A new burden of disease analysis – 2012 to 2022]

³ Osteoporosis costing all Australians A new burden of disease analysis – 2012 to 2022

⁴ AusICUROS - The Australian Study of Cost and Utilities Related to Osteoporotic Fractures

⁵ Abimanyi-Ochom et al. Osteoporos Int. 2015 Jun;26(6):1781-90.

The study found that fractures significantly reduced health related quality of life; the loss in HRQoL was sustained over at least 12 months. At a population level, the loss was equivalent to 65 days in full health per fracture.

Results showed that:

- ♦ In total, 64% were admitted to hospital
- ♦ Hip fractures accounted for 44% of hospitalisations
- ♦ The average length of hospital stay was 7.5 days
- ♦ Average length of stay increased with age
- ♦ Approximately 73 % of total direct costs were related to hospital care
- ♦ Approximately 70% of costs related to people aged >70
- ♦ Acute hospital costs totalled \$1.14 billion when extrapolated to the population
- ♦ Direct treatment costs for hip fracture per person aged 70+ years was an average of \$32,000 per patient

The annual direct cost for fractures (including formal care) in Australia in 2012 totalled \$1.76 billion.

There have been similar findings in the USA:

“In US women 55 years and older, the hospitalisation burden of osteoporotic fractures and population facility-related hospital cost is greater than that of MI, stroke, or breast cancer.

Prioritisation of bone health and supporting programs such as fracture liaison services is needed to reduce this substantial burden.”⁶

Impact on health related quality of life (HRQoL) has been underestimated because figures are based on the National Health Survey and on osteoporosis not fracture. It has been found that in the 12 month period after a subsequent vertebral fracture there was a significant decrease in four out of five HRQoL domains (Silverman 2001; Figure 2).

⁶ Singer et al. (2015) Burden of illness for osteoporotic fractures compared with other serious diseases among postmenopausal women in the United States. Mayo Clin Proc. 2015 Jan;90(1):53-62.

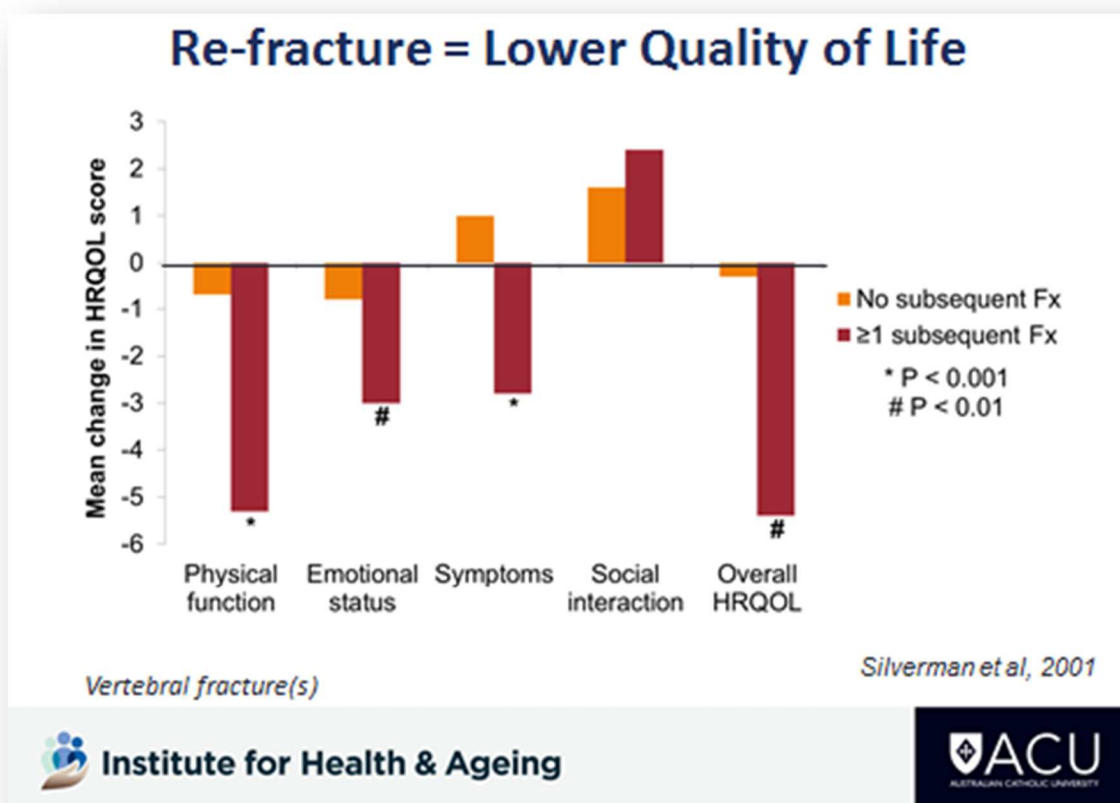


Figure 2. Change in health related quality of life score for people with secondary fracture (red) compared to those with no secondary fracture (orange).

“Secondary fracture is associated with significantly lower quality of life.”

In 2012, it was estimated from AusICUROS data that 18,500 older Australians sustained a secondary fracture after already sustaining fracture(s) in the last 5 years. The cost of secondary fracture for those 18,500 was estimated at \$223 million, with 47% of the cost due to hip fracture (Figure 3).

It has been estimated that the cost to avert 25%, or approximately 4,500, re-fractures by treating 9,000 people would be \$6.3 million, yet the cost to treat the same number of re-fractures is \$54 million. A small investment can therefore save a significant amount, even with modest assumptions.

With the ageing population in Australia, the predicted number of fractures and re-fractures is anticipated to rise steadily, along with associated costs.

Re-fractures in 2012 cost \$223 million (previous fracture in the last 5 years)

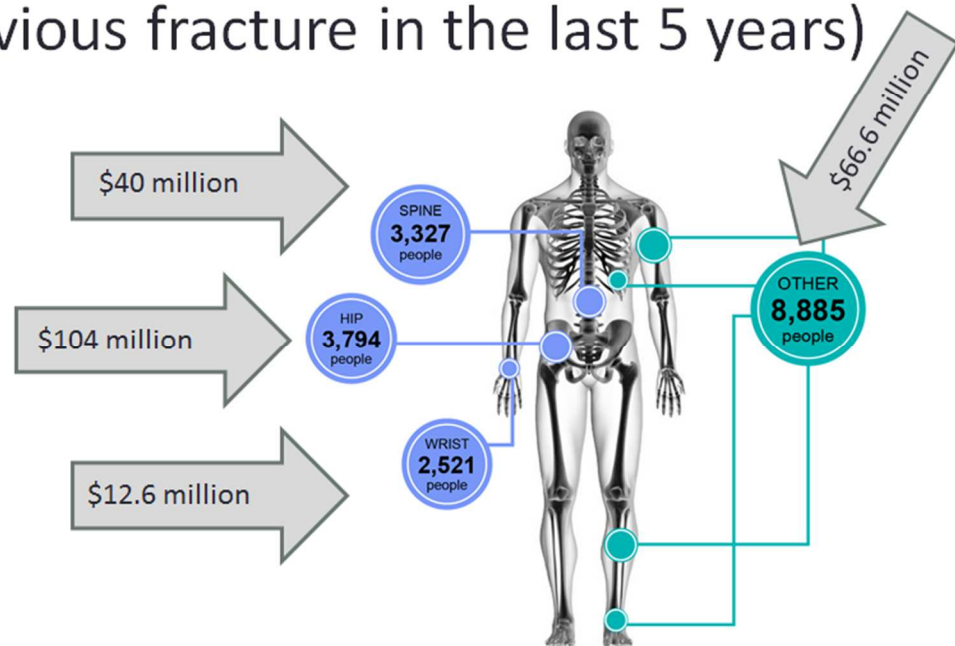


Figure 3. The cost of secondary fracture in Australia in 2012.

The current situation

Prof Markus Seibel

ANZAC Research Institute and ANZBMS

The osteoporosis care gap

In Australia, less than 20% of patients who suffer from a fragility fracture are appropriately managed to prevent a further fracture.

Approximately 50% of people who present to hospital with a hip fracture have sustained a prior symptomatic non-hip fragility fracture (e.g. of the wrist). These breaks are an early warning signal for osteoporosis and their frequency and close association with subsequent fractures highlights the need to investigate and treat patients who present with a first fracture.

In 2003, a study of 305 fracture patients at an Australian tertiary hospital found that only 15.5% of patients received appropriate pharmaceutical care on discharge.⁷ Two further Australian studies of post-fracture management in general practice also observed low treatment rates. A study by Eisman and colleagues⁸ included 88,040 postmenopausal women from 927 Australian GP surgeries and found that 29% had at least one low-trauma fracture. However, of these only 28% were on any specific therapy for osteoporosis. In 2008, Chen *et al.* studied 37,957 patients seen in general practice in Australia and found that 17,754 had spine x-rays, of which 30.1% showed evidence of vertebral fractures yet only 3.8% of those 17,754 individuals were receiving current specific treatment for osteoporosis.

Chen and colleagues concluded: "This study has confirmed low rates of treatment in primary care even in individuals who have already suffered a prior fracture or have other risk factors. This study highlights the need for further exploration of barriers to osteoporosis management in the primary care setting."⁹

In Australia 75% of women aged over 50 years who qualify for osteoporosis treatment are not receiving osteoporosis treatment (Figure 4).

We are up there with the world's worst practice, denying treatment to those at the highest risk of further fracture.

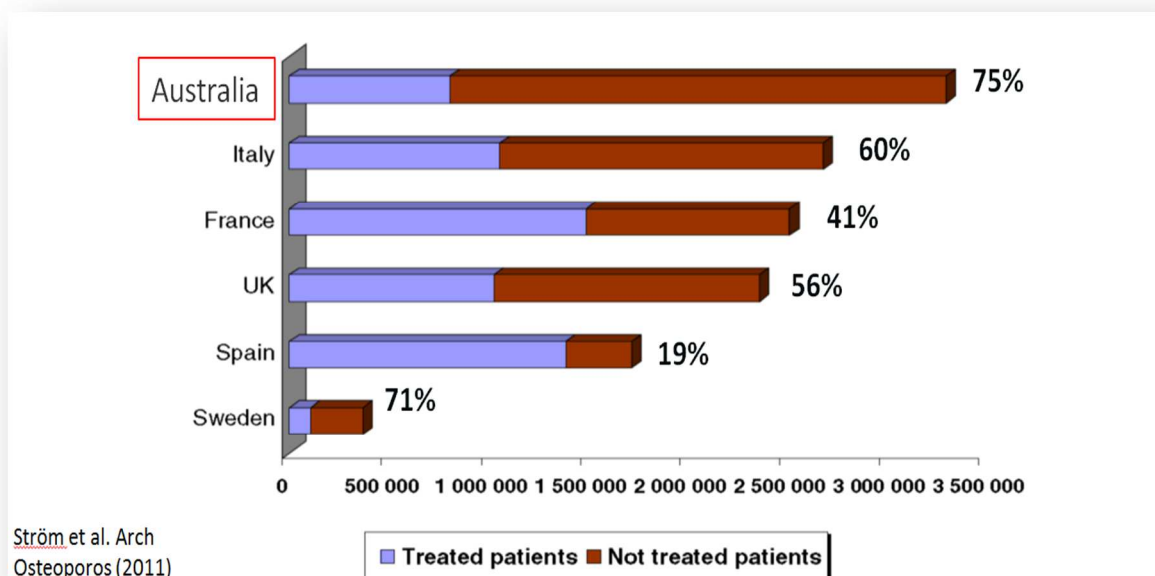


Figure 4. The proportion of treated women compared to the total female population above 50 years eligible for treatment (2008).

[Source: Strom et al. Arch Osteoporos 2011]

⁷ Nickolls C, Honours Thesis University of Sydney 2003

⁸ Eisman et al. J Bone Miner Res. 2004 Dec;19(12):1969-75.

⁹ Chen et al. Osteoporos Int. 2009 Mar;20(3):491-6.

“Half of all patients who present with a hip fracture have had another fragility fracture previously. These patients virtually announce themselves, warning us that they are likely to have a hip fracture in the future. Unfortunately, we don't listen. We fix their current fracture and send them home with no further investigations or treatment plan.”

The need for renewed action

Up to four out of five people presenting with an osteoporotic fracture are being denied effective fracture prevention. This is unacceptable practice as the risk of re-fracture increases significantly with the initial fracture, and then again with every fracture after that (Figure 5). The ageing of our population will have a significant impact on the problem of re-fracture, further increasing the burden on the healthcare system and the economy.

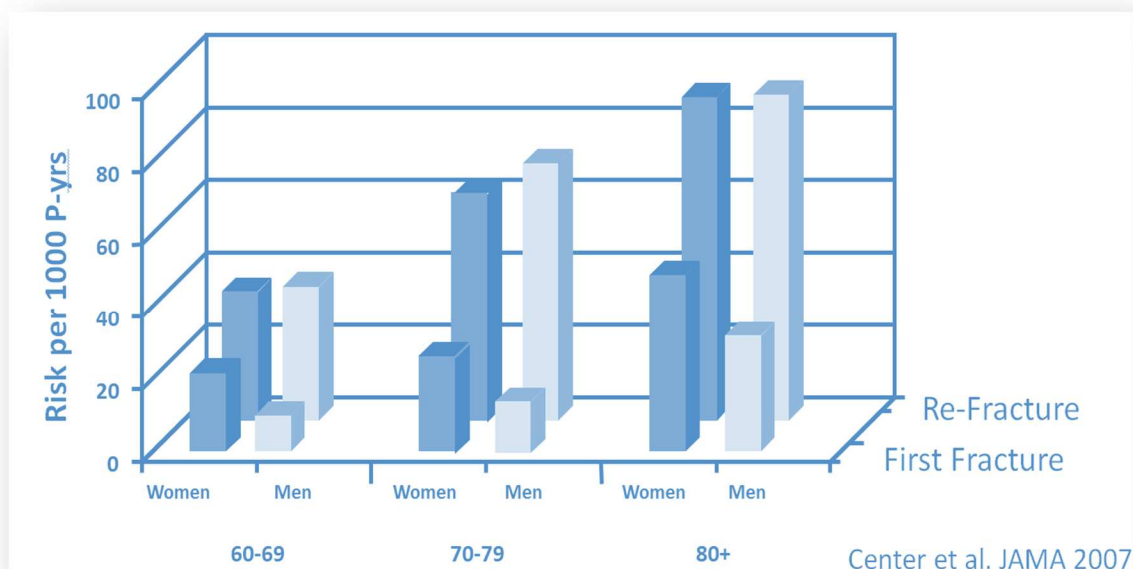


Figure 5. Risk of subsequent clinical fracture after first fracture,
[Source: Center et al. 2007]

Up to 75% of those who were independent before a hip fracture have difficulties walking or achieving their previous level of independent living within one year following their hip fracture.

In the period 2002-2008, re-fractures accounted for 16,225 hospital admissions, with an average length of stay of 22 days. This represents a substantial avoidable cause of morbidity, mortality and cost.

Why is this completely unacceptable?

- ♦ People fracture again
- ♦ People get sicker with each fracture
- ♦ People die from fragility fractures and their consequences

Why do we let this happen?

- ♦ Osteoporosis has no prestige
- ♦ Older patients with osteoporosis have no lobby group to advocate for them
- ♦ There is a lack of awareness among patients and health professionals
- ♦ Osteoporosis competes with other age-related disorders, and often loses out
- ♦ There is no peak body for secondary fracture prevention

Why have past initiatives failed?

- ♦ We haven't been focussed enough
- ♦ We haven't had every stakeholder on board
- ♦ We haven't had funding

Despite three white papers in 2001, 2007 and 2013, and the inclusion of osteoporosis as a National Health Priority (2002), actions on osteoporosis care and fracture prevention have not matched the rhetoric.

"We have a consensus – something needs to be done."

National and international initiatives in osteoporosis care

Paul Mitchell

"Hip fracture is all too often the final destination of a thirty year journey fuelled by decreasing bone strength and increasing falls risk."

"There is a great opportunity to break the fracture re-fracture cycle."

There are a number of secondary fracture prevention initiatives worldwide.

What are the elements for success of a Secondary Fracture Prevention Program?

Identification

All men and women over 50 years of age who present with fragility fracture are identified by the program.

Investigation

As per relevant local/regional/national guidelines, those at risk undergo BMD testing and fracture risk assessment through evaluation of clinical risk factors for osteoporosis and falls risk assessment.

Initiation

Where appropriate, osteoporosis treatment is initiated by the Secondary Fracture Prevention (SFP) Program and referral is made to a falls prevention service.

Further elements for a successful SFP program include the presence of an individual who coordinates the whole program so that patients are captured and managed as appropriate. In the long term, audits and follow-up of patients are important for quality assurance and to optimise adherence to treatment.

These worldwide initiatives have provided the evidence-base needed to scale to the population level.

A meta-analysis published in 2013 analysed the outcomes from all of the different types of secondary fracture prevention initiatives worldwide.¹⁰

The intervention types were divided into four groups, from A to D, with A representing a '3i' SFP Program, encompassing identification, investigation and initiation of osteoporosis treatment where appropriate, and B representing a 2i SFP program, and so on. The research demonstrated that type A and B models produced significantly better outcomes (Figure 6).

"When we talk about SFP programs, the intense models that undertake a lot of the organisational work to get that initial care plan going, those are the ones that are delivering."

¹⁰ Ganda et al. Osteoporos Int. 2013 Feb;24(2):393-406.

Model	BMD Testing	Osteoporosis treatment
Type A: 3i SFP Program model	79%	46%
Type B: 2i SFP Program model	60%	41%
Type C: 1i SFP Program model	43%	23%
Type D: Zero i SFP Program model	-	8%

Figure 6. Secondary fracture prevention programs: A systematic review and meta-analysis [Source: Ganda et al. 2013]

How do alliances in other countries operate?

The National Bone Health Alliance (NBHA) in the USA is probably the biggest alliance set up to date and is a public-private partnership. NBHA was established in 2010 and has 29 non-profit members, a number of private sector members and 5 government liaisons (CDC, Medicare, FDA, NIH and NASA). The collective reach of NBHA includes 100,000 health care professionals and 10 million consumers.

The vision of NBHA is:

"To improve the overall health and quality of life of all Americans by enhancing their bone health."

Their aim is to address the priorities of the Bone Health Summit National Action Plan:

- ♦ Promote bone health and prevent disease
- ♦ Improve diagnosis and treatment
- ♦ Enhance research, surveillance and evaluation

A 20/20 vision of reducing fractures 20% by 2020 was established as the goal.

In the award winning "2 million 2 many" campaign, which involved images of a cast mountain, the message was "If you or someone you love breaks a bone, request a test" (Figure 7). A fracture prevention website called Fracture Prevention CENTRAL was also established in 2013¹¹ with the aim of helping healthcare organisations and professionals coordinate post-fracture prevention and care.

¹¹ Fracture Prevention Central website www.FracturePreventionCentral.org



Figure 7. NBHA 2 million 2 many campaign.

The NBHA is run by only three highly capable full-time staff, physically housed within the US National Osteoporosis Foundation.

What has the impact of the NBHA initiative been?

The NBHA initiative was established in 2010 and data from the US National Commission for Quality Assurance Annual Report shows that the impact has been significant (Figure 8). The proportion of women receiving BMD testing and/or treatment for osteoporosis has risen steadily since the introduction of NBHA initiatives. Prior to this, rates were stagnant at around 20%.

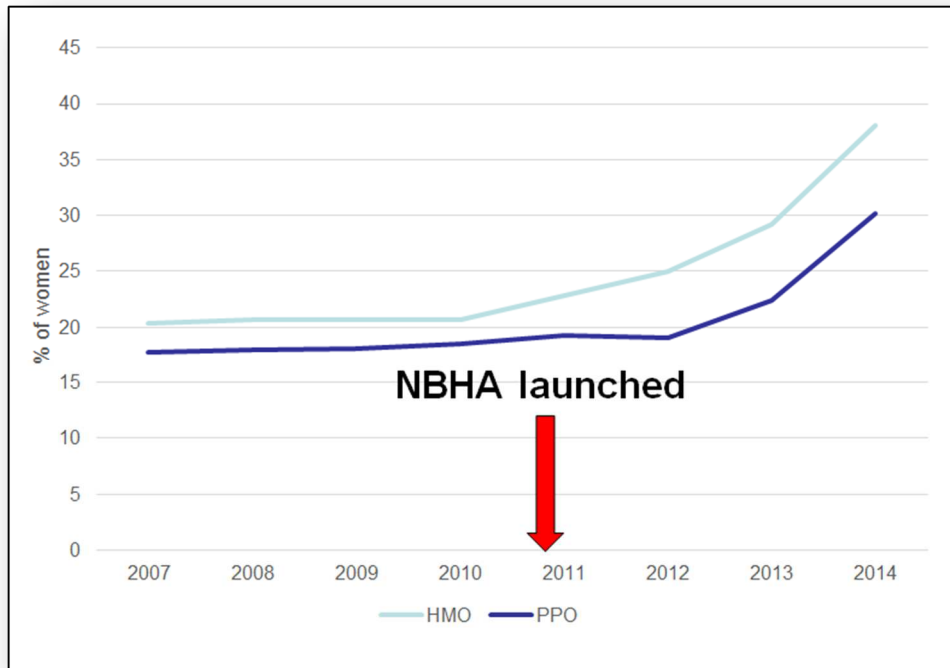


Figure 8. Post-fracture osteoporosis care in the United States: Proportion of women aged 65 - 85 years who had bone mineral density (BMD) testing and/or treatment for osteoporosis. HMO = Health Management Organisations; PPO = Preferred Provider Organisations. [Source: NBHA]

“The proportion of people receiving appropriate care in the US is escalating rapidly.”

In the UK, the Falls and Fracture Alliance,¹² and in New Zealand, The BoneCare 2020 Alliance, are also making headway in their respective countries.

In New Zealand, in the space of less than two years, all relevant organisations have worked together collaboratively to implement a systematic approach to hip fracture care and prevention for older New Zealanders. There has also been a call for the establishment of a NZ Hip Fracture Registry and universal access to SFP programs by December 2015, an objective which is on track to be realised.

From the programs running worldwide, there is **clear evidence** that secondary fracture prevention programs significantly reduce fracture risk:

¹² UK Falls and Fractures Alliance <https://www.nos.org.uk/about-us/public-affairs/falls-and-fractures-alliance>

Australia: Concord FLS, Sydney

Repeat fracture rates over a 4 year period were 80% lower, with a rate of 4.1% in the intervention group compared to 19.7% in the control group.

Canada: St. Michael's Hospital, Toronto

Modelling of the FLS reported a 9% reduction of secondary hip fracture rates within the first year of operation.

United Kingdom: Glasgow FLS, Scotland

Between 1998 and 2008, hip fracture rates in Glasgow decreased by 7.3% compared to a 17% increase during the same time period in England, where only 37% of localities operated an FLS by late 2010.

United States of America: Kaiser Permanente

In 2008, a 37% reduction in hip fracture rates was reported for the population served by the Kaiser Permanente Southern California system.

This corresponds to the prevention of 935 hip fractures in the year 2006 (2,510 hip fractures were predicted by actuarial analysis, and 1,575 fractures were actually observed).

Comments from the attendees

"We now have adequate evidence that organised programs for secondary fracture prevention work and are cost-effective.

We can now make a very strong case to government to say that this is worth doing from a financial and health point of view." – **Bruce Armstrong**

"In our study two similar hospitals were compared, one with a fracture liaison service and one without. The re-fracture rate was reduced by 40% at the hospital with the FLS."

"We are targeting the most at risk people, we are actually achieving a significant benefit." – **Gabor Major**

"What seems to be clear is that there is a teachable moment after people have fractured and it's not very long, only about three months." – **Paul Mitchell**

"There is confusion among the general public about the terms bone break and fracture – we need to be careful with terminology." – **Ann Robinson**

"The best programs are ones which can engage patients and their carers" – **Katherine Stone**

"Your return on investment is very favourable if you target women in the over 50 age group with a previous fracture." – **Paul Mitchell**

"This issue needs to be on the orthopaedic surgeons' agenda. We need to think about follow up care. Osteoporosis needs to end up on the discharge summary." – **Andreas Loeffler**

What are the key elements of a rational approach that this alliance wishes to advocate for?

Purpose: To ensure that all Australians with a fragility fracture are appropriately managed to prevent further fractures.

Goal: To widen the uptake of 'best practice' for the treatment of all patients with osteoporotic fractures to prevent secondary fractures.

Objective 1

Address all patients who present to hospital with a fragility (minimal trauma) fracture

Objective 2

Widen this approach to general practice

Key elements of the 'case' for SFP action

Burden of disease

- ♦ Patients are readily identifiable
- ♦ Morbidity and mortality is avoidable, potential to improve quality of life
- ♦ Large potential to reduce costs
- ♦ Programs are worth investment both from a financial and health point of view
- ♦ Intervention timing is a critical variable

Key elements of an Australian approach

At the clinician level the Australian approach should involve a shift from immediate fracture repair to a clear pathway that involves a multi-disciplinary team. Patient involvement and education should be paramount, as should education of funders and system decision-makers. There needs to be a clear goal and engagement of all stakeholder groups. No single group can achieve this goal. We have the opportunity to form an Alliance which benefits from the experience of others worldwide.

"We're trying to make sure that all of those people that break something don't break something else. And what we understand from the evidence base is that probably the best way to do that globally is to have the dedicated coordinator based systems that ensure that everything is done that should be done" – **Paul Mitchell**

"The aim is to have a Secondary Fracture Prevention Program in every health district that sees patients with osteoporotic fractures." – **Markus Seibel**

"The way to get to a minister is through the public. If you miss out on teaching people who are affected by this problem – that is patients and their carers – you miss out on a huge opportunity to actually influence that minister."

*"From a strategic advocacy point of view... you miss a whole segment of influence if you haven't actually educated the public. The person who is most invested is the person with osteoporosis, and their families and their carers, as long as they understand. - **Katherine Stone***

"Do you, The Hon Sussan Ley MP, want to be known as the Health Minister that implemented a program nationally that saved health expenditure, and saved lives and saved disease burden? – That's how it should be framed"

The need for a national alliance for secondary fracture prevention

What is the interest in forming a National Alliance for Secondary Fracture Prevention?

The results from the Delphi process

Markus Seibel

The Delphi method was developed as a way to achieve consensus of opinion among experts. "The Delphi method solicits the opinions of experts through a series of carefully designed questionnaires interspersed with information and opinion feedback in order to establish a convergence of opinion."¹³

Between September and November 2015 the Delphi process was conducted among a group of key stakeholders. This was a consensus process with Round 1 involving qualitative surveys (14 participants) and Round 2 involving quantitative surveys (15 participants). The process was supported by Prof Helena Teede's group at Monash University, Melbourne.

Results were divided into 'Agree', 'Neutral' or 'Disagree' for analysis (although the questions posed included strongly agree/agree and strongly disagree/disagree, these were combined to simplify the analysis).

Domain 1: What is the purpose of a National Alliance for secondary fracture prevention?

A National Alliance should enable member organisations **to speak with one voice** to governments to maximise the likelihood of getting heard. **Majority (12/13) agree.**

A National Alliance should be **explicitly focused** on elimination of the current secondary fracture prevention care gap through providing a mechanism to drive the implementation of Secondary Fracture Prevention (SFP) Programs across Australia. **Majority (12/13) agree.**

A National Alliance should engage with **broader** issues such as raising awareness for osteoporosis, education of medical professionals and the public, guideline development, and promotion of bone health across Australia. **Majority (7/13) disagree.**

¹³ RAND corporation www.rand.org

Summary - Domain 1 – Majority views

The Alliance should:

- ♦ speak with one voice to governments
- ♦ focus on implementation of Secondary Fracture Prevention (SFP) Programs
- ♦ not engage with broader issues

Domain 2: What should the National Alliance achieve?

The National Alliance should strive to have members from all relevant professional and patient societies in Australia. **Majority (12/13) agree.**

The National Alliance should achieve an agreement on a national system for identification of people with a **first fragility** fracture and their referral for consideration of reduction in risk of subsequent fracture. **Majority (11/13) agree.**

The National Alliance should achieve an agreement on a standardised approach to evaluating risk of osteoporosis in **older adults without known history of fragility fracture (i.e. primary fracture prevention)**, and the optimal investigation and care pathway for those identified as at high risk. **Majority (10/13) disagree or neutral.**

The National Alliance:

- should urge the Federal government to implement quality improvement programs to support Australian general practitioners to deliver clinically effective and cost-effective long-term management of all fragility fracture patients.
- demonstrate the cost-effectiveness of Secondary Fracture Prevention Programs to State and Federal governments. **Majority (12/13) agree.**

The National Alliance should support implementation of the ANZ Hip Fracture Registry and associated guidelines/ clinical care standards. **Majority (10/13) agree.**

Summary - Domain 2 – Majority views

The Alliance should:

- ♦ have members from all relevant professional and patient societies.
- ♦ achieve an agreement for secondary but not primary fracture prevention.
- ♦ achieve its goal through targeted advocacy of nationwide provision of Secondary Fracture Prevention Programs by State and Federal governments.
- ♦ implement quality improvement programs to support GPs.
- ♦ demonstrate the cost-effectiveness of Secondary Fracture Prevention Programs to State and Federal governments.

Domain 3 - How should the Alliance be governed?

The National Alliance should be governed by a **Board** constituted of representatives of member organisations. **Majority (8/13) agree.**

The National Alliance needs a **strong but inclusive** executive with defined tasks allocated to **subcommittees**. **Majority (9/13) agree.**

The first thing to do for the National Alliance is to develop a **constitution**, a clear **strategic plan** and **terms of reference**. **Majority (9/13) agree.**

The National Alliance should not be a separate structure but **integrated under the umbrella of ANZBMS and Osteoporosis Australia**. **Majority disagrees or neutral (10/13 neutral; 3/13 agree).**

Within the first year of establishment, the National Alliance should seek to have **liaison officers/ points of contact** representing the Federal and all State governments. **Majority agrees or neutral (11/13).**

The National Alliance should **not invite Pharma** companies to become members. **Majority agrees or neutral (12 agree or neutral; 1/13 disagree).**

Summary - Domain 3 – Majority views

The Alliance should:

- ♦ be governed by a Board constituted of representatives of member organisations.
- ♦ have a strong but inclusive executive with tasks allocated to subcommittees.
- ♦ develop a constitution, a clear strategic plan and terms of reference.
- ♦ be a separate, independent structure (5 for, 5 neutral, 3 against).
- ♦ not invite pharma companies to join.

Domain 4 - How should the Alliance be funded?

The National Alliance should be funded by

- contributions from member organisations only. **Majority (8/13) neutral.**
- philanthropic donations. **Majority (11/13) agree.**
- the government. **No clear majority (5/13 neutral; 5/13 agree; 3/13 disagree)**

The National Alliance requires a suitably skilled professional Executive Director, with administrative support, to execute the aims of the Alliance. **Majority (11/13) agree.**

Summary - Domain 4 – Majority views

The Alliance should:

- ♦ have a skilled professional Executive Director with administrative support
- ♦ be funded by philanthropic donations and/or the government.

Roundtable discussion

What is the purpose, mandate and nature of an alliance?

What is critical to the success of an alliance?

What are the converging interests or issues for members of the alliance?

The National Alliance for Secondary Fracture Prevention needs to be one united voice to have a clear focus on secondary fracture prevention.

The National Alliance needs to target Commonwealth and State governments to embed secondary fracture prevention within the health system, across primary and acute care settings.

The primary driver of advocacy to government should be cost-effectiveness.

"I think it is very important that this organisation, if it's formed, does not appear to compete with the member bodies. If this Alliance can be funded by the member organisations we remove that problem; it should be our first position."

– Bruce Armstrong

"Osteoporosis Australia is concerned that the alliance potentially raises the risk of competing for funding both from the government and the very crowded market of the philanthropic foundations." - Greg Lyubomirsky

The relationship between OA and The Alliance needs clarification. There is potential for competition, however, it is clear that OA alone cannot achieve the aim by itself.

Governments do not want to hear from multiple organisations for funding of the same condition. However, so far the government has not listened to the voice of single, small organisations, such as OA. Hence, an Alliance that includes OA might be more powerful and will increase the likelihood of securing funding and support for secondary fracture prevention.

OA has been working for the past 2-3 months on a proposal to take to the government. The proposal includes a nationwide audit of fracture liaison services. However, the ANZ Hip Fracture Registry already has these data. Prof Close indicated that in 2015, only one FLS has been implemented in Australia, bringing the national total to a mere 20 services. The group needs to see the proposal to be submitted by OA.

The Alliance is a group that has a highly focused aim: to minimise secondary fracture incidence. Its goals are aligned with the aims of OA.

The Alliance must remain independent. It cannot be part of one of its members; otherwise it is not an Alliance and likely to lose its voice and impact.

It is pivotal that OA becomes part of the Alliance in campaigning for Secondary Fracture Prevention, but remains an independent organisation for all its other activities such as education, patient representation and osteoporosis awareness in general.

"It is my position and the position of my Board that we will always support the Alliance. I think it is a fantastic voice and a very powerful voice. But we need to be very careful that it doesn't create another burden on the marketplace."

"We're happy to be part of this and make sure it is a success."

- Greg Lyubomirsky

A small group will get together with OA in order to bring back an understanding of the current situation and ways to resolve the issues around OA.

Designing a national alliance

What do we want a national alliance to achieve?

A SWOT analysis was conducted with attendees in a roundtable discussion setting. A SWOT Analysis is a useful technique for understanding strengths and weaknesses, and for identifying both opportunities open to us and the threats we face.

Forging a national alliance to advocate for Secondary Fracture Prevention Programs to prevent secondary fracture

Key results from SWOT analysis:

Current strengths to nurture <ul style="list-style-type: none">♦ One voice – agreed purpose/ shared vision♦ The alliance is independent of any members♦ Broad reach representation – critical mass of organisations involved to ensure progress♦ Good evidence and robust argument♦ Strong clinical commitment	Current weaknesses (plan to overcome) <ul style="list-style-type: none">♦ No agreed funding model♦ No dedicated resources♦ No shared plan♦ Lack of expertise in advocacy and securing funds♦ Lack of some key organisations e.g. private health insurance providers; AMA; radiologists
Probable opportunities to exploit <ul style="list-style-type: none">♦ NHMRC – CFA falls & fractures♦ Approach providers/ insurers e.g. Medibank Private, BUPA♦ National Hip Fracture Registry – expand?♦ Set own agenda♦ Reach even more members	Probable threats (plan to avoid) <ul style="list-style-type: none">♦ Fail to work collaboratively<ul style="list-style-type: none">○ With OA○ Asymmetry of contributions○ Perception of lack of independence♦ Reliance on voluntary effort of busy people (loss of focus/ burnout)

Finalisation of the key operating principles for the national alliance

Designing an independent alliance for secondary fracture prevention

The principle is to stay independent of any specific member and therefore optimises the opportunity for many to contribute. An Alliance cannot be part of one of its member organisations.

The National Alliance will exist only for the purpose of ensuring Secondary Fracture Prevention Programs become the standard of care in Australia. Once this has happened, the Alliance will disband.

The National Alliance will not impinge on or threaten the role or funding of member organisations.

The National Alliance will bring to bear research, clinical (acute & primary), consumer, carer, insurer interests and the influence of their constituents, since none can do this acting alone.

Alliance governance and management

A number of options exist and there was discussion around this topic.

Ideas included establishing a Board (as that was the preferred outcome from the Delphi process) that governs the National Alliance.

The Board could take the following form:

- ◆ Organisations are members/ Organisations nominate Board members
- ◆ The Board has 3 permanent and 5 rotating members
- ◆ The Board has 3-4 executive positions (President, Vice-President, Secretary, Treasurer) with two year terms

The Board will tackle the following key tasks:

- ◆ Development of a strategic plan
- ◆ Ensures all members views are taking into account
- ◆ Ensures all members are kept informed

The Board would oversee the work of an Executive Officer supported by a secretariat (paid hours).

What kind of entity should the National Alliance be?

Principles:

- Independent of any specific member
- No individual member has the clout to make Secondary Fracture Prevention Programs happen alone.
- Optimises opportunity to contribute - every member can contribute
- Exists for the purpose that FLS become a feature of Australian healthcare; It does not need to be an organisation in perpetuity.
- The Alliance is not here to impinge, take over or encroach on the territory of any member organisation

Option A

The National Alliance is set up as a separate legal entity

- ♦ Constitution and operating capital provided initially by member organisations
- ♦ Able to contract, employ and secure funds.

Option B

Osteoporosis Australia is the legal entity (subject to OA Board approval)

- ♦ OA is the entity with who others contract and invest
- ♦ OA is the employer of the National Alliance paid staff
- ♦ OA ensures the National Alliance receives investment funding for secondary fracture prevention initiatives.

The US Alliance is separately constituted, but physically housed within National Osteoporosis Foundation (NOF).

The NBHA in the US is the one that has been instrumental in change. Its medical voice is absolutely important but the consumer voice is pivotal, too. We must have both. The strength in number is critical. If every single organisation here backs the concept 100%, governments will take notice.

Action Plan

Where to from here?

Steering group

A steering group needs to be established to start actioning the outcomes from this meeting. The following attendees volunteered to be on the steering group:

- Markus Seibel (Chair)
- Bruce Armstrong
- Jacqui Close
- Mark Kotowicz
- Colleen Langron
- Greg Lyubomirsky
- Gabor Major
- Davor Saravanja
- Katherine Stone

Memorandum of understanding

Distributing a memorandum of understanding (MOU) to all member organisations should be high on the steering committee's agenda.

The Memorandum of Understanding will include:

- ♦ A clear vision and mission statement for the National Alliance for Secondary Fracture Prevention
- ♦ Member organisations will be asked to affirm the following:
 - To make a clear commitment to actively contribute to the National Alliance
 - To agree in principle to the vision, purpose and principles of the National Alliance

What is critical to our success? What must we now focus our attention on?

- Deal with weaknesses early
- Design strategy for funding model / business model
- Consult other groups for input on how they are set up

Next steps - Action items

Members:

- To provide MOU and terms of reference templates to Markus.
- To raise options and provide feedback from the OA board who meet during the week beginning 23 November 2015 (Greg, Melita)

Steering Group:

- To schedule first meeting (Markus, Ivone)
- To work on and refine a clear vision and mission statement
- To determine any other organisations that should be invited/included in the National Alliance
- To draft and disseminate MOU within the next 30 days
- Aim to have MOUs returned from organisations and the National Alliance formed by February/March 2016.

Thanks and acknowledgements

Prof Seibel extended his gratitude and thanks to all attendees. He also noted the significant contribution of Ivone Johnson and Paul Mitchell who were co-organisers. He thanked Lynnette Glendinning for facilitating the meeting and Ruth Hadfield for record keeping.

Appendix 1

MEETING AGENDA

10.00am	SESSION 1 – SECONDARY FRACTURE PREVENTION: KEY ELEMENTS OF THE CASE FOR A NATIONAL APPROACH	
10:00am	<ul style="list-style-type: none"> Welcome and purpose of the Forum Overview of the program and introductions 	<i>Markus Seibel</i> <i>Lynette Glendinning</i>
10.15am	<ul style="list-style-type: none"> Update on the burden of disease 	<i>Kerrie Sanders</i>
10.35am	<ul style="list-style-type: none"> The current situation – the Osteoporosis Care Gap. The need for renewed action. 	<i>Markus Seibel</i>
10.55am	<ul style="list-style-type: none"> National and international initiatives in Osteoporosis Care 	<i>Paul Mitchell</i>
11.10am	<ul style="list-style-type: none"> What are the key elements of a rational approach that this group wishes to advocate for? 	<i>Table group and plenary discussion</i>
11.25am	<ul style="list-style-type: none"> Summary of a national approach and the 'case' for it 	
11.35am	Break	
11.50am	SESSION 2 – THE NEED FOR A NATIONAL ALLIANCE	
12.10	<ul style="list-style-type: none"> What is the interest in forming a National Alliance for Secondary Fracture Prevention? <ul style="list-style-type: none"> results of the Delphi process what is critical to the success of an Alliance? determine the purpose, mandate and nature of an Alliance clarify converging interests and issues for Members 	<i>Markus Seibel</i> <i>Group discussion</i>
12.45pm	Lunch	
1.15pm	SESSION 3 – DESIGNING A NATIONAL ALLIANCE	
	<ul style="list-style-type: none"> What do we want a National Alliance to achieve? How will we take the Alliance agenda forward – key elements of strategy (including funding) What Alliance governance and management arrangements will <ul style="list-style-type: none"> assure Members? ensure effectiveness? Finalise the key operating Principles for a National Alliance 	<i>Table groups</i> <i>Plenary discussion</i>
3.00pm	Break	
3.10pm	SESSION 4 – ACTION PLANNING	
	<ul style="list-style-type: none"> Key elements of a Memorandum of Understanding <ul style="list-style-type: none"> what needs further discussion the process and next steps 	
4.00pm	<ul style="list-style-type: none"> Summary and close 	

Appendix 2

Alphabetical list of participating organisations

ANZAC Research Institute
Australia New Zealand Bone and Mineral Society
Australia New Zealand Orthopaedic Research Society
Australia New Zealand Society for Geriatric Medicine
Australian College of Nurse Practitioners
Australian Commission for Safety and Quality in Healthcare
Australian Faculty of Rehabilitation Medicine
Australian Orthopaedic Association
Australian Physiotherapy Association
Australian Rheumatology Association
Bupa Health Insurance
Carers New South Wales
Dietitian Association of Australia
Endocrine Nurses Society of Australia
Endocrine Society of Australia
Garvan Institute of Medical Research
Institute for Health and Ageing
Medical Oncology Group of Australia
National Health and Medical Research Council
National Hip Fracture Registry
Osteoporosis Australia
Public Health Association of Australia
Royal Australasian College of Physicians
Royal Australasian College of Surgeons
Royal Australian College of General Practitioners

List of attendees

Bruce Armstrong	Public Health Association
Heather Buchan	Australian Commission on Safety and Quality in Healthcare
Jackie Center	Garvan Institute of Medical Research
Fun Chan	Endocrine Nurses Society of Australia
Jacqui Close	ANZ Hip Fracture Registry
Melita Daru	Australia New Zealand Society for Geriatric Medicine
David Findlay	Osteoporosis Australia
Kirtan Ganda	Australia New Zealand Orthopaedic Research Society
David Jesudason	National Health and Medical Research Council
Mark Kotowicz	Australian New Zealand Bone and Mineral Society
Colleen Langron	Royal Australasian College of Physicians
Andreas Loeffler	Endocrine Society of Australia
Greg Lyubomirsky	Australian Physiotherapy Association
Gabor Major	Australian Orthopaedic Association
Paul Mitchell	Osteoporosis Australia
John Parikh	Australian Rheumatology Association
Ann Robinson	Australian New Zealand Bone and Mineral Society
Kerrie Sanders	Osteoporosis New Zealand
Davor Saravanja	Royal Australian College of General Practitioners
Markus Seibel	Endocrine Nurses Society of Australia
Natalie Stapleton	Institute for Health and Ageing, ACU
Katherine Stone	Australian Orthopaedic Association
	Royal Australasian College of Surgeons
	Australian New Zealand Bone and Mineral Society
	ANZAC Research Institute
	Dietitian Association of Australia
	Carers New South Wales

Apologies

Amy Bowen	Australian College of Nurse Practitioners
Chris Dalton	Bupa Health Insurance
Steven Faux	Australian Faculty of Rehabilitation Medicine

Support staff

Lynette Glendinning	Facilitator, Tempo Strategies
Ivone Johnson	Executive Officer, ANZBMS
Ruth Hadfield	Medical writer
Ross McLeod	Observer – eSYS Development Australia

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